

## **LETTER FROM A STUDENT**

## Dear Student,

Congratulations—you're getting ready to head off to college! I know this transition can be stressful, but your time at college is going to be an amazing experience. Diabetes can seem like a big hurdle to jump over, but just remember all of the things diabetes has done to shape you into the person you are today: responsible, diligent, organized, and not to mention you're probably a whiz at doing math in your head. These traits will all serve you well in college.

Personally, I know that the scariest part of moving to college was navigating a new social scene. Diabetes can feel like an isolator, but you'll be surprised at how many people will find your diabetes interesting and, if you can believe it, cool. At first, I was terrified of telling people about my diabetes. Over time, I've learned that being open about my diabetes can lead to some amazing friendships with people who want to learn more and are genuinely interested in understanding diabetes.

You may feel nervous about moving away from home and figuring out how to manage your diabetes on your own. Just like any transition, the first few weeks will be a big experiment. As you try to adjust to your new schedule, you may experience fluctuations in your blood sugar that will require extra attention. I'm sure this isn't the first time that you've dealt with crazy blood sugars, so I know you can handle this! Trust me, I know how frustrating this can be, but I can't stress enough how important it is to make your diabetes a priority during the first few weeks of school – you will thank yourself in the long run if you make your health a priority now.

Just like any other college student, you may have times when you feel the need to prioritize staying up late to finish up a paper or cramming for a large exam. I want you to remember that no matter what, your health and safety comes first. I get that sometimes diabetes management can fall on the back burner, and that's perfectly normal. Don't be too hard on yourself if you miss one bolus, one blood sugar check, or don't carb count for that one meal. Most importantly, don't forget to enjoy college. It is such an important time for your personal and professional growth and you are going to make connections that will last a lifetime. Remember to enjoy it, take care of yourself, and have the time of your life!

## **Zachary Hall**

Albion College, Class of 2018

## **TABLE OF CONTENTS**

Letter from a Student		Left	
Introduction		1	
Sponsors		3	
<b>Preparing for College</b>		4	
Common Challenges to Expect When You Get to Campus		6	
Family Communication Agreement		8	
Looking at Schools Guide		10	
Registering for Accommodations for Standardized Tests		14	
Registering for Accommodations on Campus		18	
Preparing to Move Out: A Timeline		30	
Life on Campus		38	
What is a CDN Chapter?		40	
Clinical Care: Finding a New Doctor		42	
Managing Sick Days		46	
Having "The Talk" with Friends and Roommates		50	
Emotional Wellbeing: Dealing with Burnout		52	
Drinking with Diabetes		54	
Rights During Emergency Situations		56	
Entering the Working World		58	
Technology on Campus		60	
Data Sharing		62	
First Break Home		68	
Other CDN Resources	Rack	Cover	

Thank you to the CDN Clinical Advisory Committee Members for their assistance in developing the content for these booklets.

## INTRODUCTION

Thinking about college?
Packing and counting down
the days? Props to you.

Oh yeah, and you have diabetes, too? We get it, we've been there.

## **DISCLAIMER**

This booklet contains no medical advice. Discuss any medical decisions with your doctor. All information shared by peers is regarding their own personal experiences. The information contained in this booklet was reviewed by the American Diabetes Association® and TCOYD.

Young adults with type 1 diabetes (T1D) from across the country have come together to compile the wisdom in the pages of this booklet. They want you to worry less, learn from their mistakes, and enjoy this exciting time in your life (hint: it only happens once).

We at the College Diabetes Network (CDN) are here to help you navigate all the stages of college. So while this booklet is truly awesome (we're not biased or anything), be sure to sign up for our free student membership to stay up to date on all of our other programs and resources that can benefit you.

## **The College Diabetes Network**

The College Diabetes Network (CDN) is the only organization focused exclusively on helping teens and young adults with T1D transition to independence–facilitating peer camaraderie and programs, and providing life-changing information–giving young adults the confidence to take ownership of their health to live a full life without compromise.

CDN equips young adults with the confidence to manage T1D while in college by providing information on topics that, let's be real, aren't typically the highest priority during a typical endo appointment. Some of these topics include, but are not limited to:

- Scholarships
- Drinking with diabetes
- ▶ Talking to friends and roommates about diabetes
- ▶ How to communicate effectively with family members
- ▶ Emotional wellbeing
- Accommodations and student rights
- ▶ We've got it all—and more.

**CDN Student Membership** You can sign up online for free at collegediabetesnetwork.org/signup! You don't need to be part of a Chapter, or a college student, to take advantage of these benefits. CDN student members receive:

Benefits, promotions, and giveaways from our partnering organizations and Corporate Members, and exclusive access to internship and job openings.

Notifications about clinical trials and patient advisory committees looking for participants. Alerts on new issues affecting the diabetes community and updates from other CDN students across the country.













The content in these booklets has been reviewed by





Thank you to our distribution partners











## We want you to spend your time searching for schools, not scouring the internet for diabetes resources.

## CHRISTINA ROTH CEO AND FOUNDER

The College Diabetes Network would like to thank our 2018 project sponsors Dexcom, JDRF, Insulet Corporation, Lilly Diabetes, Novo Nordisk, Sanofi, and Tandem Diabetes Care, for their support of this project and their commitment to easing the transition from high school to college for young adults living with diabetes. We would also like to thank the American Diabetes Association and TCOYD for reviewing these materials, and AADE, NCBDE, and Children with Diabetes for being distribution partners. Together with these partners, we are combining forces to make resources and support available to any family in the United States going through this transition—helping to simplify, rather than further complicate it. The content of these booklets is, as always, based on the views and experiences of the CDN and our students. The content is entirely our own, and has been developed independently from any and all sponsors/partners and may or may not represent their views and opinions. So, to sum it up: CDN student wisdom—real tips, real experiences, no bull, and a little bit of sass.





## COMMON CHALLENGES TO EXPECT WHEN YOU GET TO CAMPUS

While everyone has different experiences at school, it's important to keep in mind that some challenges are common and regularly mentioned by students. We want to share some of these challenges before you leave so you can be better prepared to tackle them once you are on campus.

## **CHALLENGES**



## Having a sporadic schedule and no routine

College students are known for having crazy schedules. Your classes take place at various times on different days; homework, studying and social events dictate your free time, and your eating and sleeping schedules are a slave to the above factors each day. This can be a tough environment in which to manage diabetes because it can make seeing patterns difficult.



## **Stress**

With exams and ten-page papers that you've procrastinated on until the last minute, it's inevitable that you're going to experience a great deal of stress at various times throughout college. The problem with stress is that in some people it can raise blood sugars to epic proportions.



## **Dining hall**

The dining hall can present a challenge to students with diabetes. It can be tough to access nutritional information and serving sizes, making carbohydrate counting and bolusing feel more like picking lottery numbers.

### **OUICK TIPS**

- ✓ Keep some sort of routine each day—whether it's the time you wake up, when or what you eat, and/or when you go to the gym.
- ✓ Be prepared. Keep necessary diabetes supplies on you at all times (i.e., meter, insulin, a syringe and low treatment) so that you're ready to go if you and your friends do something spontaneous.
- ✓ Stay away from carb- and sugar-heavy items at the dining hall. Instead, opt for the foods that you can easily look up the nutritional info for (i.e., brown rice, baked potatoes, chicken, burgers, etc.).

## **SOLUTIONS**

It may be impossible to keep the same exact schedule each day, but that doesn't mean you can't have some consistency. Pick a couple elements of your day—i.e., breakfast, lunch, or going to the gym—and try to do them at the same time every day. This will help to structure your day a bit more, and give you a starting point for determining what adjustments might need to be made in your diabetes management.

The more consistent you are with your day the easier it will be to spot patterns.

Figure out what helps to relieve your stress—and make time for it. If your blood sugar won't come down in the morning, do some yoga, play intramural kickball, or lie down and watch a movie. Of course, just in case this doesn't work, make sure that you've registered for accommodations with your campus Disabilities/Auxiliary Services office. That way, if your blood sugar won't come down on the morning you're supposed to take your final, you have the option to reschedule.

When possible, try to limit eating foods with high carb counts (like pasta and desserts). Instead, opt for vegetables, fruits, protein (like chicken or tofu), and other foods that you know or can look up the carb count for. Lastly, know your staples. Choose a few foods that are usually available and try to find out the exact carbohydrate counts.

If the dining hall is not meeting your needs, remember that you can stock your dorm with packaged and microwaveable food options (i.e., yogurt, oatmeal, protein bars, etc.).

## **FAMILY COMMUNICATION AGREEMENT**

Students, you probably want your family to get off your back about your diabetes.

A good way to help establish trust and quell your family's anxieties is to establish a communication agreement to set boundaries and expectations.

You can refer to this example as a guide to create your own family communication agreement so that everyone feels comfortable with the transition.





## **STUDENTS I promise to...**

- ✓ Wear a medical alert ID.
- ✓ Find support on my campus.
- ✓ Register with Disabilities Services.
- ✓ Keep low supplies on hand, always.



## **CAREGIVERS** As long as you promise to...

- ✓ Not ask what my blood sugar is unless I bring it up.
- ✓ Let me be the one to tell other people about diabetes.
- ✓ Send me care packages and/or help pay for extra supplies.
- ✓ Not overreact or get mad at me when I tell you the truth.

ORE IDEAS

When will you check-in? How often? How often will you discuss your blood sugar? What can be said? Who will bring it up?

## **LOOKING AT SCHOOLS GUIDE**

# It may be hard to believe, but soon you will be graduating from high school and heading off to college!

College is a new and exciting time in your life, but it also requires a lot of planning. You've probably started spending some of your free time checking out schools, talking to friends and family about college, and beginning to put together an idea of what you want for the next four years. It's okay if you don't know what you want yet—that's what looking is for!

Make sure you know what kinds of things you care about in a school—then you'll know what questions you want to ask. There is a lot to consider when choosing a college, including what majors they offer, the type of campus culture, residence life, and so much more! The key thing to remember is that diabetes shouldn't affect where you decide to go to school.

## **BEST OF LUCK IN YOUR SEARCH!**

Visit our site throughout your college experience for more resources, tips, and support!

**COLLEGEDIABETESNETWORK.ORG** 





## **LOOKING AT SCHOOLS GUIDE** (Continued)

## **Scholarships**

There are a number of scholarship opportunities for students living with diabetes—so start browsing. We strongly suggest checking our scholarships webpage ASAP so that you have enough time to apply. Many scholarships are due before you even commit to a college.

## **CDN Chapters**

CDN consists of campus Chapters all across the country that are made up of students just like you. These Chapters are student-led groups that allow students to connect with others who get it. Find out if there is a Chapter at the schools you are interested in by checking out the map on our website. Don't worry if you've already fallen in love with a school that doesn't have a CDN Chapter. CDN can easily help you create one at your school or put you in touch with local students living with diabetes!

## **Disabilities/Auxiliary Services**

Many students don't think of diabetes as a disability, but when it comes to being prepared, registering with your school's Disabilities/Auxiliary Services when you get to campus can be a good move. At this point in the game, just check to see if they've had previous experience with students with diabetes and how they have helped accommodate them in the past. Check out the "Registering for Accommodations" section of this guide for more info!

## **Health Services/Clinical Care**

Make sure you are aware of where you would seek medical care for your diabetes and what the campus health center is capable of helping with. Some questions to ask admissions/health center staff at the schools you tour:

- Does the health center have experience with students living with diabetes on campus?
- Can you help them to create a plan for how to work with students with T1D?
- What services does the health center provide?
- Can you get your prescriptions filled at an on campus pharmacy?

## **CONNECT WITH STUDENTS:** chapters@collegediabetesnetwork.org

Get a firsthand account of what life is like on campuses you are interested in and ask students about your diabetes-related questions.

### **Residential Life**

Dorms are an important part of campus life. Consider the following questions:

- ▶ How many roommates will you have?
- Will you have a resident director and/or hall advisor?
- Is there kitchen access in the dorm?
- ▶ Can you have a fridge and/or microwave in your room?
- ▶ What does first year housing generally look like? Where are the dorms?
- Is there any specialty housing you might want to apply for?

## **Dining Services**

Eating on campus can be a challenge without proper planning. Make sure that you are aware of what each school provides in terms of dining services. Consider the following questions when you are looking at the dining options on campus:

- ▶ How does the meal plan work? Are there options that will suit your needs?
- Is there access to supplemental food (i.e., cafés, restaurants, stores on campus, etc.)?
- What are the hours of operation for the dining hall? What is open when the dining hall is closed?
- Where are dining halls located relative to resident halls and classes? And how many are there?
- Are there gluten free options (if you also have celiac disease)?
- Does the dining hall provide nutrition information and/or measuring cups? (Note: you can advocate for yourself once on campus and request these—see the 'Dining Hall Eating' section of our site!).

## **Access to Supplies**

You'll need to restock your diabetes supplies while at school. Consider how and where you'd get your supplies at each school you are considering.

- Where is the closest pharmacy? Is there an easy way to get there?
- ▶ How does the mail room handle packages that need to be refrigerated (insulin)?
- Does the health center help with supplies?

## **Distance from Home**

There are schools all across the country and you might find yourself loving a school far from home. Make sure you consider what it would be like to be a one-hour car ride vs. a six-hour plane ride away from home. Distance from home is a very important consideration for all college students but especially for students living with diabetes. How far are you comfortable taking your diabetes from home? For some people, the distance might be too much; for others, it is exactly what they want.

## REGISTERING FOR ACCOMMODATIONS FOR STANDARDIZED TESTS

Standardized tests, while stressful, can be essential for your higher education. Because of their importance, the rules can be strict on what you are allowed to bring into the room during exam time. Many students with T1D apply for accommodations in case they run into any diabetes-related issues, such as needing extra breaks to check your blood sugar or having a low snack. While you may already be registered for accommodations with your school, you will have to apply for separate accommodations for these tests.

We recommend talking with your parents and your diabetes care team to determine what sorts of accommodations you will need during a test.

## **Helpful Hints**

- Make copies of all accommodation application materials and bring them to your test.
- Stay organized and on top of filing your paperwork before the deadlines (a calendar with important dates and reminders will be a huge help).
- > Start as early as possible.



## **SOME COMMON TESTING ACCOMMODATIONS FOR T1D INCLUDE:**



## **Extended testing time**



## Extra breaks

(for glucose checks, bathroom, etc.)



Bringing food, water, glucose, meter, CGM and pump/shots into the room



## SAT®/ACT® GUIDELINES FOR ACCOMMODATIONS

## FIRST STEP LETTER FROM A PROFESSIONAL

If you are applying for accommodations for either the SAT® or the ACT®, you will need an official letter from your doctor to provide proof that you have diabetes.

### Make sure this letter includes:

- √ Age of diagnosis 
  √ Course of medical treatment
- √ Limitations diabetes puts on your testing experience
- √ How accommodations can help you
- \* both SAT® and ACT® have a supplemental form for a teacher to fill out to strengthen your application for accommodations.

### **GOOD TO KNOW**

- For both tests, if you are under 18 your parent or guardian will need to sign a medical information release form when applying for accommodations.
- Start as early as possible. You only have to apply for accommodations once for each test, so giving yourself ample time increases the likelihood you will get the accommodations you need, and allow you to focus on studying for the exam rather than stressing about your accommodations.
- Stay on top of your school administrator/disability officer. It is up to you to hold them accountable for submitting your request. Regularly checkin with them to make sure they have submitted your request, or you may not be approved in time. Be persistent but polite.
- Only request accommodations that you absolutely need. Requesting excess accommodations can weaken your application and potentially hurt your ability to get the accommodations you truly require.
- Keep records of the accommodations you receive. If you end up taking tests for graduate school (GRE®, MCAT®, etc.), a record of the accommodations you received on past exams will make your application process much easier.

### **SAT®**

The SAT® is run through the College Board and uses Services for Students with Disabilities (SSD) to register students for accommodations.

- You will have to register through your high school's disability officer, because they are the only people who have access to submit the request through SSD. If you are registered for accommodations at your high school, they will already be familiar with your needs as a T1D.
- ▶ The whole process takes about seven weeks to be approved, so start as early as possible.
- ➤ The College Board website has a list of accommodation deadlines for tests, so keep an eye on those and mark them in your calendar!

## **After Approval**

- Once you are approved for accommodations, you will receive an SSD number via email and an Eligibility Letter. You will use these when registering for the SAT®.
- Once you apply for the accommodations through the College Board and are approved, you will be approved until one year after your high school graduation date. Your accommodations are also approved for all other College Board tests, including SAT® Subject tests, PSAT®, and AP exams.
- On test day, make sure to bring your SSD Eligibility Letter and double check that your accommodations are in place.

## **ACT®**

The ACT® uses a similar process, but a different platform than the College Board for accommodations. It is called the Test Accessibility and Accommodations Center (TAA).

- Like the SSD system, only your high school's disability officer can access the TAA, so the same approach applies with the ACT® test.
- With the SAT®, you apply for accommodations before you register for the test, but with the ACT® you request accommodations when you register for the test itself. From there, ACT® will email you instructions on how to proceed with the process. It will take approximately two to four weeks for approval.

### After Approval

➤ You will receive an email from ACT® with your approval, TAA PIN, and a list of your approved accommodations.

## REGISTERING FOR ACCOMMODATIONS ON CAMPUS

Many students with diabetes don't register with the Disabilities/ Auxiliary Services office at their school.

(Some students simply don't know that it's an option and others are just completely turned off by the term 'disability'.)

Give us a few minutes to explain why it's a good idea.

## Reasons to Register



### **PLAN BEFORE AN EMERGENCY**

If you aren't registered with Disability Services, you aren't guaranteed any sort of accommodations for problems that may arise due to your diabetes. You cannot register for accommodations retroactively. If you fail or miss a test because of low or high blood sugar and you haven't registered, you'll have to accept the grade.



## DON'T SELL YOURSELF SHORT

It is scientifically proven that being low or high can seriously affect your academic performance. Perhaps you can get a passing grade on a test while your blood sugar is high, but imagine what you could get if it wasn't. Set yourself up for success.



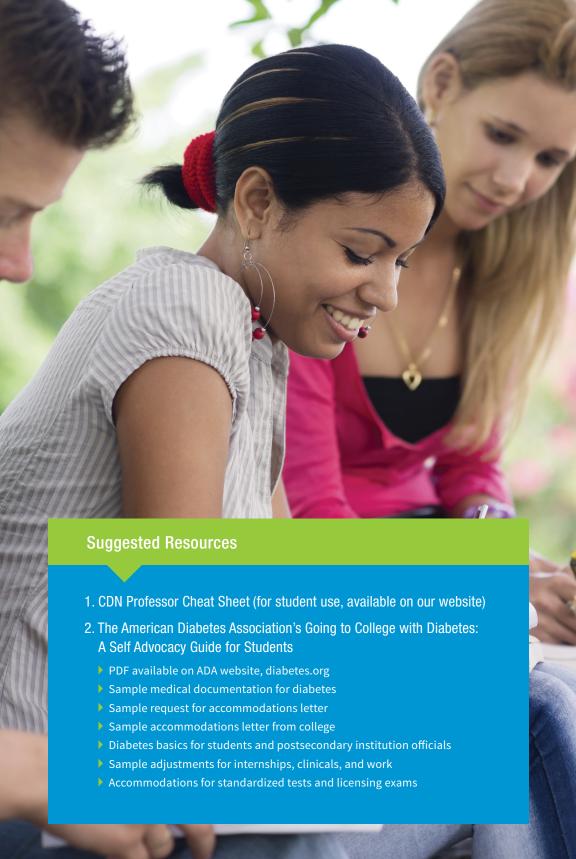
## **ADVOCATE FOR YOURSELF**

Most professors are extremely accommodating, but once in a while you encounter a professor who isn't. Registering with Disabilities Services overrides whatever rules your professor has established around food and drinks in the classroom, the use of technology ('texting' on your pump), or the ability to make up exams.



## **DON'T LET DIABETES LIMIT YOU**

Accommodations can also extend to housing, dining, and registering for classes. This can include where you live, roommate situations, meal plans, and early class registration.



## REGISTERING FOR ACCOMMODATIONS

## **How to Register**

## **Identify** who is in charge of accommodations

Each campus is different. The office in charge of accommodations could be called Disabilities Services, Auxiliary Services, Accessibility Services, or something similar. Try searching 'Disabilities Services + [Your Campus Name]' to find the office you should connect with. Still unsure? Try checking in with the health center, residential life staff, or student affairs.

## Register as soon as you are on campus

Reach out to the office responsible for accommodations as soon as you get to school. Many campuses offer a very brief window for students to register for accommodations, so don't miss it. If you have an on-campus orientation over the summer, we suggest checking in with this office then.

## **Provide appropriate documentation**

While every campus is different, it's a good idea to have the following documentation from your doctor:

- A diagnosis of your diabetes along with its symptoms (believe it or not, not everyone is familiar with diabetes or what it means).
- An explanation of how your diabetes is a disability.
- A request for specific accommodations along with an explanation of why they are appropriate.

## **KNOW YOUR RIGHTS**

Learn more on the 'Advocacy and Student Rights' section of the CDN website: collegediabetesnetwork.org/advocacy

## **POSSIBLE ACCOMMODATIONS**

While everyone is different, sometimes it can be hard to know what type of accommodations might be useful for you as you begin college life. It's up to you to communicate with the staff in charge of accommodations about what else you may need. Don't be afraid to advocate for yourself. Check out some of these possible accommodations for students with diabetes and why they may be helpful for you.

## **CLASSROOM ACCOMMODATIONS**

Accommodation	Why It's Important	
Ability to consume food or drink, if needed.	Some professors don't allow food or drinks in their classrooms.	
Establishing a response system with faculty if you become unwell.	If you have a diabetes-related emergency, a response system will help establish protocol for how a faculty member can assist.	
Ability to use a note taker or provision of notes, or obtain audio/video recordings of class lectures.	If you are absent for a diabetes-related issue, a note taker or audio/video recording can help you keep up with the classroom material.	
Ability to perform diabetes care in class, such as testing blood sugar or administering insulin and/or ability to leave class briefly to attend to diabetes care needs.	You may be experiencing an extreme low or high blood sugar, and the ability to treat in class if desired, rather than having to leave the classroom, is critical for your health. You may also prefer, or need to, briefly leave class to attend to your diabetes.	





## **TESTING/EXAM ACCOMMODATIONS**

## Accommodation

## Ability to have "stop the clock" accommodations in exam

administration.

## Why It's Important

Diabetes care and management can be time consuming, and if you experience a high or low blood sugar during an exam (which affects cognitive functioning), it may take between 15 minutes to 1 hour to get back in range. The ability to pause the exam and resume when cognitive function is restored can be critical to capturing a fair performance on the exam.

Ability to bring medical supplies, including food and drink, into testing facilities.

You may need access to your diabetes management tools during a test or exam, including but not limited to a continuous glucose monitor (CGM), pump, phone or smart watch, blood sugar testing meter, insulin and syringes, food or drink, and/or other supplies.

Ability to reschedule an exam if, at the time of an exam, the student's blood sugar is out of target range. In some cases, high or low blood sugar may impair cognitive function for longer than a "stop the clock" accommodation would provide, and rescheduling the exam can allow you to perform at your true cognitive ability.

## **OTHER ACCOMMODATIONS**

## Accommodation

## Why It's Important

Ability to have priority class registration.

Diabetes is a 24/7 chronic illness that requires approximately 1-2 hours per day for you to manage. Priority registration allows you the best possibility of a consistent schedule semester to semester, which can improve diabetes management. It also provides time for meals, getting between classes, and to schedule medical appointments. Allowing you more control over your schedule can also lead to fewer incidences of missed classes or exams, as you can arrange your schedule in a way to factor in these needs and anticipate your own unique needs.

Reduced course load with full time equivalency, if needed. You may find that you struggle with the transition to college and the management of your care in a new environment. A reduced course load with full time equivalency can allow you to devote more time to your diabetes care, appropriate eating habits, and healthy sleep and exercise habits as you adjust to the college environment, without being denied scholarships or financial aid.

Ability to have a diabetes alert dog.

Diabetes alert dogs are service animals and can function as a critical and highly effective component of your diabetes management. Diabetic alert dogs can alert you to high and low blood sugars, minimizing the risk of a diabetes-related health emergency.

Ability to have a flexible meal plan.

College dining plans, especially for freshman, may not always meet your needs. A flexible meal plan can help you save money, eat better, and better manage your diabetes.

## **HOUSING ACCOMMODATIONS**

## Accommodation

## Why It's Important

Ability to have priority for specific housing options, such as housing with access to a kitchen or near a dining hall. If you are experiencing a low blood sugar, even a 5-minute walk to the dining hall can be impossible and unsafe. Kitchen access can also allow you to better manage your diabetes by knowing the exact carb counts of foods you consume, which means you are more likely to be able to regulate your blood sugar.

Flexibility with roommate options/

There are occasionally situations where you may have a roommate that was assigned to you that is so uncomfortable with certain aspects of diabetes management, such as needles or blood, that the roommate relationship is untenable. You may also be more comfortable with a roommate of your choosing as that person may have indicated that they are willing to assist you in the event of a diabetes emergency.

Ability to ensure a sleeping arrangement close to the floor.

If you wake up with low blood sugar and dizziness, a top bunk bed can pose a danger to you or make access to treatment supplies challenging.

Access to biohazard/ sharps container for student's room/living situation. You need a safe way to dispose of medical waste including hypodermic needles and other diabetes supplies.





Navigating the transition to independence at college is challenging for any student, but for young adults with diabetes—or other invisible diseases—managing physical and mental health on top of academics, extracurricular, and social life is a daunting responsibility.

That's why CDN is partnering with leading higher education and diabetes organizations to launch CDN REACH™, a multi-faceted framework designed to augment campus resources and help administrations support the wellbeing of students with diabetes and deliver upon their mission for all students enrolled.

CDN REACH™ is designed to provide administrators with the information and tools they need to reduce physical and mental health risks for their students with T1D and liability for their schools.

As part of CDN REACH™ CDN is launching a series of three new guides designed for campus administrators. These guides provide a primer on diabetes and its impact on campus life, and how staff in Student Health Centers, Disability Service Centers, and Counseling Centers can best support students with diabetes.

## HELP CDN ON THIS IMPORTANT MISSION BY LETTING ADMINISTRATORS ON YOUR CAMPUS KNOW ABOUT THESE GUIDES!



### **HEALTH SERVICES:**

For campus health professionals to better understand how to best support their students with diabetes.



### **DISABILITY SERVICES:**

For campus accessibility staff to inform about what accommodations are frequently found to be helpful for students with diabetes.



## MENTAL HEALTH SERVICES:

For campus mental health professionals to provide insight into how diabetes can affect the mental health and well-being of students.

To help you get prepared, packed, and ready to go, we put together a timeline so that you know exactly what to do and when.





## **MONTHS BEFORE MOVE-IN**

## **Create a Plan for Your Supplies**

There are many options for getting supplies while at school (for example, mail-order companies, local pharmacies, or restocking when at home).

Here are some considerations to help you create a plan well before move-in day.

- ▶ Where will you be getting supplies from?
- Where will diabetes supplies be sent?
- ▶ Who will be ordering them?
- ▶ Who is responsible for making sure any payments for supplies are made?
- How long will your supplies last?
- ▶ How will you know when to reorder them?
- ▶ Where will you go to restock your low supplies and how will you get there?
- When will you need to update their prescriptions?
- ▶ Where will your prescriptions be filled?

## **Don't Forget About Back-up Supplies**

If you don't have one already, be sure to get a backup meter from your endocrinologist or at your local pharmacy before you leave for school—it's a good idea to have another meter in case your first one breaks or gets lost. Also make sure to have syringes (even if you're on a pump), long-acting insulin, and anything else that may be helpful if your main method of care fails.

## **Staying Cool**

You'll want to have a plan for refrigerating your insulin. You might want to consider purchasing a mini-fridge for your room instead of using a public fridge. For short trips or travel, the FRIO® cooling case only requires water to keep your insulin from getting warm.

## **Think About Sharps**

Where will you dispose of sharps? Sometimes your school's Disability Services or Health Center will have a sharps container, or you can order one—ask your endocrinologist. You can also use an empty opaque laundry detergent container. Next, figure out where to keep it. Many students find that under the bed is easiest.

## 3 MONTHS BEFORE MOVE-IN (Continued)

## **Schedule Appointments**

We know sometimes it's a few months before you can be seen by a provider and once you get to campus it might be hard to find time. Schedule your next few appointments before you leave—you can always reschedule later if you need to.

## **Make the Space**

Storing all those diabetes supplies in a small space takes some planning. If you're going to loft your bed for extra storage, some schools require you to call and pre-order the lofting package ahead of time. Risers can also be bought at stores that sell dorm supplies and can add a few inches off the ground. Many students use plastic storage bins to house supplies while living in the dorms to better use a tight space and keep things organized.

## **Get a Flashlight**

It's a good idea to have a small lamp or flashlight near your bed so you can see what you're doing when you wake up to check or treat a late-night low. That way you don't have to turn on the light and wake up your roommate. Headlamps are a good hands-free option.

## Connect with Your Roommate Over the Summer

Send a text, Facebook message, or email to your roommate over the summer and get to know each other a little bit. You can tell them about your diabetes if the time is right, but if not, it will be much easier to talk to them about it at school if you know each other beforehand. If you live close to each other, meet up for coffee or lunch to get to know each other better. When you do tell them about your diabetes, refer to the "Having 'The Talk' with Friends and Roommates" section of this guide.



#### **Create a Communication Plan**

When you go off to school, you don't want your parents constantly asking about your diabetes. In order to avoid any conflict between you and them, create a communication plan for all of you so that you get the freedom you want and they get the peace of mind they need.

Refer to CDN's 'Family Communication Agreement' on page 8 as a guide as you and your family create something that works for you. And try to cut your parents some slack— they only have your best interests at heart. Keep in mind that this agreement is going to change as your needs and their needs change throughout your years in college.

Have an open discussion about what is and isn't working with your diabetes team. College brings about a lot of changes—changes in your lifestyle, blood sugars, and diabetes management. Talk to your diabetes team before you leave and make a communication plan to use while you're at school.

# Here are some questions that you and your healthcare team should answer together in order to create a plan:

- ✓ What is the best method of communication for both you and your provider to connect? Email? Phone? There are a lot of free apps that let you easily log and share your blood sugars with your doctor!
- ✓ What will you do if there's an emergency and you need to see an endocrinologist right away?
- ✓ How often will you be scheduling check-up appointments with providers and when?



#### **MONTHS BEFORE MOVE-IN**

#### **Get a Medical Alert ID**

We know that sometimes it's hard to find the right medical alert ID, but it's especially important to have one while you're away from your normal support system. Check out page 39 for info on how to become a CDN student member and get discounts!

#### **Get Some Bags**

Make sure you go to school with a couple different bags that can hold all of your belongings and your diabetes needs—especially when you're traveling back and forth between home, going on weekend trips, vacations, and just trekking across campus!





#### **MONTH BEFORE MOVE-IN**

#### **Prepare a Sick Day Kit**

It's important to take care of yourself—and your blood sugar fluctuations—when you're sick. Prepare a sick day kit before you leave, as getting sick can come on suddenly. This is a great way for your parents to help you prepare.

Check out page 45 for suggestions on what to include!

#### **Create a List of Contacts**

Before you leave, sit down with your parents and create an important contacts list. Make sure you have the phone numbers and contact information for all your diabetes-related needs, as well as important people.

**This includes:** insurance company, pump company, CGM company, pharmacy, mailorder supplier, endocrinologist, diabetes educator, and any other doctors you see.

Don't forget to put the contacts and numbers into your phone so that you have them when you need them!

PACK!! All the items we've been discussing? Make sure to take them all with you!



#### **Have Some Low Snacks Ready**

You might go low carrying boxes up hills and stairs, unpacking all of your things, and constructing shelving units—have some low supplies ready on move-in day.

#### **Check Your Fridge**

As silly as it sounds, make sure your fridge is plugged in. And remember to check the temperature settings—some high settings freeze insulin.

#### **Go Food Shopping**

Take a trip to the local grocery store with your parents and load up on low supplies and snacks for the room. Try some of these student-approved snacks that are good to keep in your dorm room to treat lows, highs, and general study-induced hunger.

#### **LOWS**

- Glucose tabs
- Juice boxes
- Fruit leather
- Crackers
- Sports drinks (also good for the gym and hangovers)
- Raisins
- ► Candy without fat (i.e., jellybeans or gumdrops)

#### **HIGHS**

- Water bottles
- Powdered drink mix (try the no-carb individual packets for on the go)
- ▶ Tea bags
- Fresh veggies like cucumbers or celery



#### **Make Sure Supplies Are Accessible**

That plastic bin is not going to be useful if you can't get to it. Try raising your bed so you can fit your diabetes supplies and food underneath—they should be easy to get should you need them in the middle of the night.

#### **Have a Glucagon Kit Readily Available**

It's always helpful to have a Glucagon kit in a visible place in case of emergencies. It doesn't do anyone any good if you're the only person who knows where and what it is and how to use it.

#### **Find the Closest Pharmacy**

Look for the closest pharmacy to your school and figure out the easiest way to get there. Put the information into your phone. Even if you use a mail-order pharmacy, there may be times when you need to visit a store in person.

#### **Talk to Your Roommate**

Make sure you aren't keeping your roommate in the dark about your diabetes. If you haven't brought it up already, let them know the basics about what to expect in terms of you managing your diabetes. Think back to how you decided to bring it up, and stick to the plan! If you feel comfortable, let them know they can ask questions and make it clear that you are not expecting them to take care of you.

#### **Remember Your Family**

While you're excited to move out and get started with college, keep your parents in mind throughout the process. They're probably sad and nervous that you'll be moving out of the house so try to help ease their worries whenever you can. Send them to the parents' section of the CDN website for more tips and support.







#### WHAT IS A CDN CHAPTER?

# **About CDN Chapters**

Chapters are student-led groups that allow students living with diabetes to connect with one another, learn about the latest diabetes technology and gadgets, and exchange tips and tricks for managing diabetes on campus.

#### **HOW TO GET INVOLVED IN A CDN CHAPTER:**



# VISIT OUR WEBSITE: collegediabetesnetwork.org/chapters



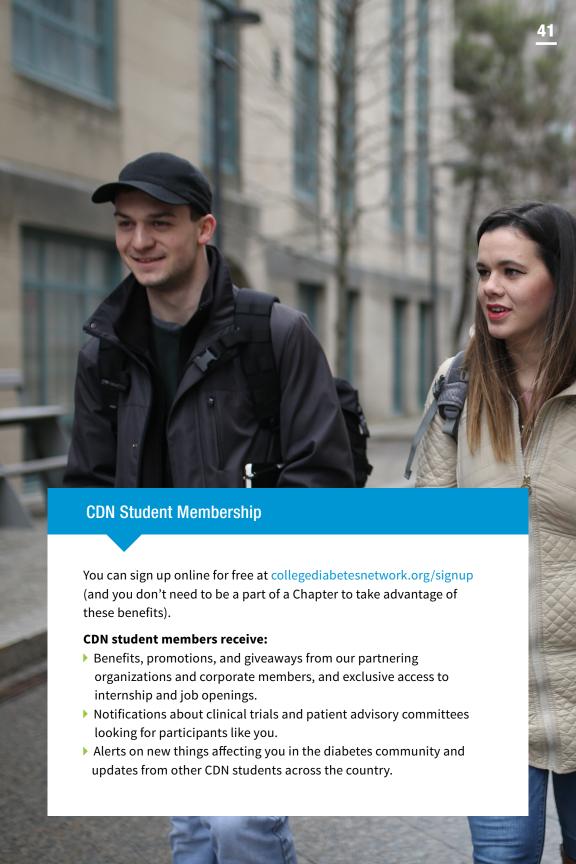
#### **JOIN OR START A CHAPTER**

- ▶ Search for a Chapter on our website.
- Contact CDN staff to join or start a Chapter at: chapters@collegediabetesnetwork.org



#### WHY GET INVOLVED IN A CHAPTER?

- Connect with other T1D young adults who get it.
- Be a part of the diabetes community on campus.
- Learn about local resources.
- Gain leadership experience.
- ▶ Participate in community service projects.
- ▶ Be a part of a national program.
- Inspire others.



There are a million things that can get in the way of you seeing your doctor once you arrive on campus, but it is extremely important to continue to do so.

We will walk you through finding a new provider and give you some tips on tackling other doctor-related challenges.



#### **Reasons to Begin Looking**

- You attend school hours away from home and are unable to see your health care provider(s) as regularly as you would like.
- You aged out from your pediatric provider.
- You feel guilty and/or not empowered after leaving appointments.
- You feel your health care provider doesn't understand or is unable to help you.

#### **How to Find an Adult Provider**

Finding the right provider, especially when transitioning from pediatric to adult care, can be a lot like dating. Personality types, approaches to diabetes management, priorities, and location are all important points to consider.

#### Take the following steps:

- Talk to your doctor about which adult providers they think would be a good fit.
- ▶ Read reviews of health care providers online.
- ▶ Contact members of the CDN Chapter on your campus and ask who they see for their diabetes management.

#### **Ask Questions**

To help you determine if a health care provider is right for you, we suggest asking the provider (or their team) the following questions, and evaluating their answers, during your first appointment:

- ▶ How much time do you spend with a patient during an appointment?
- Who does the diabetes care team consist of? (CDEs, exercise physiologist, nutritionist, psychologist, social worker, etc.)
- What do you think are the most important parts of diabetes care?
- ▶ How much personal experience do you have with T1D?
- ▶ How open are you to new technologies, research, and therapies?
- ▶ Who is on call when you are not available?
- Are you available between scheduled appointments and can I stay in contact with you remotely?
- ▶ Have you ever worked at a diabetes camp?

#### **Last Meeting: Former Provider**

- Discuss any concerns you may have about transitioning providers.
- Ask your provider's office to transfer your patient records to your new provider.

  Make sure to have the new provider's fax number.

#### **CLINICAL CARE: FINDING A NEW DOCTOR**

#### **First Meeting: New Provider**

#### **Preparing for the Appointment**

Make a call to your new doctor's office and find out exactly what you need to do before getting there. Some doctors require you to have lab work done prior to your appointment.

Be open and honest about what you want and expect from your relationship. That might be a kick-in-the-butt or acknowledgment and support. Either way, BE ASSERTIVE! Your doctor is there to help you, so let them.

Write down questions for your new doctor before your visit. In addition, try writing down what you're struggling with. Here are some questions to get you thinking:

- ▶ What has been successful in your diabetes management and what has not?
- When is the most challenging time of day?
- Are there any activities that you are struggling to manage blood sugars during?
- How does your A1c seem in comparison to how much work you are putting into managing your diabetes?
- Are you struggling with anxiety, depression, burnout, or eating disorder/body image issues related to your diabetes?
- ▶ What are the social barriers to managing your diabetes right now?
- ▶ What motivates you? What are your goals?

#### At the Appointment

- Bring a friend or family member to the appointment. They can be your support system before and after the appointment.
- Bring everything you need with you. That includes all of your diabetes supplies (meter, CGM, and pump), your insurance card, and any other paperwork that the doctor's office has requested.
- Ask questions during the appointment to clarify things and to make sure you are understanding recommendations or information from your provider.
- ▶ Take notes during the appointment so you remember what you discussed.
- Make the adjustments that your doctor has prescribed. It's easy to leave the doctor's office and forget about the changes you said you'd make. Program all of the technical adjustments into your pump as soon as you leave (or during the appointment) and make sure everything else (equations, ratios, basal rates, etc.) is written down for future reference.

Challenge	Solutions
My school is in a rural area, I don't have a car, and the nearest endocrinologist is hours away.	<ul> <li>✓ Ask your friends with cars if they'd be interested in going on a road trip.</li> <li>✓ Schedule your appointment around the same time as another Chapter member and carpool together.</li> <li>✓ Schedule appointments to take place while you're at home for breaks or holidays.</li> <li>✓ Explain your situation to your doctor and ask if they can do virtual check-ups.</li> </ul>
I know that my HbA1c is not where I want it to be and I don't want to feel worse than I already do about it.	<ul> <li>✓ Your doctor's job is to help you better manage your diabetes and identify what's not working. If your doctor is making you feel guilty, consider finding another who supports you.</li> <li>✓ Read through the questions to the left of this table for ideas to discuss and work on with your doctor.</li> </ul>
I don't have enough data for a constructive appointment. (e.g. I don't check frequently)	✓ Again, it's your doctor's job to help you better manage your diabetes and identify what's not working. A good doctor will help you figure out how to get back on track. ✓ As you know, diabetes isn't just about the numbers. You should be able to have a productive appointment with your doctor, even if you're lacking a large amount of data.

#### **Schedule Your Next Appointment**

Whether with the same doctor, or a new one, schedule your next endocrinologist appointment ASAP so that you don't forget. You can always reschedule it if you need to, but get it on the calendar right away.

#### **Evaluate Your First Visit**

Do you like your doctor? Do you feel more empowered about your diabetes care than when you walked in? Were your questions/concerns addressed? These are really important questions to ask yourself. If the answer is 'no', then consider finding another doctor.

#### **MANAGING SICK DAYS**

Sneezing. Coughing. Aching. Exhaustion. Whatever your symptoms, getting sick happens to everyone. Usually, it comes at just the wrong time (hello, finals). While you might be feeling crappy, it's really important to keep an even closer watch on your diabetes management while you're sick. Here are some tips to keep in mind next time you're stuck in bed watching Netflix and sneezing up a storm.

#### **Important Tips for Sick Days**

- Ask a friend to check in on you. College is a much different environment than home. Unless you tell someone you're really sick and can't get out of bed, you can't expect them to know. Maybe you need more low supplies from the store. Maybe you need to be taken to the hospital. Maybe you won't need anything at all. Whatever the case may be, your friends won't mind checking in to make sure you're okay.
- Check your blood sugar often—at least every two to three hours.
  Many people have trouble controlling their blood sugar when they're sick and it's important to keep a close eye on it.
- Continue taking insulin. While you may need to make adjustments to your basal/ bolus rates to compensate for higher or lower than normal blood sugar levels, you still need insulin.
- Hydrate. Hydration is important while sick regardless of whether you have diabetes or not, but it's especially important for you as dehydration is a risk factor for diabetic ketoacidosis (DKA).
- ▶ Check for ketones. You can still have ketones even if your blood sugar is in range.

#### **Contact Your Healthcare Provider If You Experience Any of the Following:**

- You have moderate (0.6 mmol/L) to large (1.6+ mmol/L) amounts of ketones in your blood or urine.
- Your blood sugar is not coming down despite correction doses.
- You have symptoms that might signal ketoacidosis, dehydration, or some other serious condition—your chest hurts, you're having trouble breathing, your breath smells fruity, or your lips/tongue are dry and cracked.
- You've been sick or had a fever and aren't getting better.
- You are vomiting and can't keep food down.

# Sick Day Ready Kit

Prepare this list before you leave for school (we're looking at you, Mom and Dad.) The following items will come in handy when you start feeling crappy and don't want to see anything but the inside of a pillow:



#### GLUCAGON-YOUR SAFETY NET

Do you carry glucagon with you when you leave your home? Do you keep glucagon easily accessible where you sleep? Do your close friends and family (roommates) know how to use it?

No? That's okay - you're not alone. Not many people with diabetes carry glucagon with them, or even know what it does.

Glucagon is a hormone that raises blood sugar. Anybody who takes insulin is at risk of low blood sugar because of insulin's effects, and while some fast-acting carbohydrates are usually enough to bring blood sugar levels back to normal, in severe cases, people with diabetes may experience inability to swallow, unconsciousness, or seizures due to hypoglycemia.

In those cases, a glucagon emergency kit can save your life. Keeping one handy and showing others how to use it is a simple way to protect yourself from the worst.

There are great innovations in glucagon products on the horizon for people with diabetes - ones that will make this safety net even easier and more accessible for people with diabetes. Be on the lookout for news from CDN as these therapies become available!





CDN is dedicated to ensuring our members have information regarding all of the options available to them. The companies shown above are CDN Corporate Members. CDN receives no benefits, financial or otherwise, related to product sales.



# Chances are they will want to learn more about what diabetes is and how they can help you. The bottom line is that it's really

Struggling to explain to your friends why you have a 'pager' on your waist? Moving in with someone new? Or maybe you've been living with the same people for a while and you haven't gotten around to anything past, "Sorry for the test strip you found in your shoe the other day."

The bottom line is that it's really important for the people around you to know (and understand) your diabetes. While it's normal to be self-conscious sometimes, just remember that your diabetes and all of the gadgets that come along with it make you unique—and your friends will probably think it's kind of cool. Let us help you start the conversation.

#### THINGS TO EXPLAIN

#### **Type 1 diabetes**

There are A LOT of people who don't understand what diabetes is or the difference between type 1 and type 2. Try something like the description below, or practice a version that feels right to you.

"The pancreas produces insulin, which helps to convert sugar, starches, and other food into energy. My pancreas doesn't work so I have to measure insulin to put into my body myself. I am able to do that using [your insulin delivery method]. It's not an exact science, so that means I have to constantly monitor my blood sugar to make sure it isn't too low or too high and make adjustments when it is."

"There is really nothing that I can't do or eat. I just have to do a bit more planning."

#### For 'The Talk' We Suggest:

- ✓ Use humor to help diffuse any tension you feel about telling your friend about diabetes.
- ✓ Feel comfortable and confident in what you're telling them. The more comfortable you are talking about it, the more comfortable they are going to feel about it!
  ✓ Start simple! Then add details from there.

#### **What Happens if Blood Sugar is Too High/Low**

It's crucial for your friends to understand and recognize what being high and low looks like. Be sure to explain your personal symptoms so they can provide assistance if necessary.

"When my blood sugar is high it means that there is too much sugar in my body. I may be thirsty, aggravated, tired, or confused. I treat it by taking more insulin. When this happens I don't feel well and may want to relax until I feel better."

"When my blood sugar is low it means that I don't have enough sugar in my body. I may start feeling tired, confused, dizzy, or sweat a lot. I treat it by eating or drinking something with fast-acting sugar in it like juice or glucose tabs. When this happens I don't feel well and may not want to talk much until my blood sugar rises again."

#### **How Friends Can Help**

Even if you've never had a diabetes-related emergency where you've needed help before, you need to explain this part to your friends—just in case.

"I (haven't/have) had a serious low blood sugar when I was too low to treat it myself. That being said, you should know to call 911 if this were to happen (again)."

Keep in mind that Glucagon may cause nausea. If Glucagon is used, make sure people know to keep you on your side to avoid aspiration. If vomiting occurs, call 911 immediately.

#### What Else They Can Do (also, maybe what they shouldn't)

What you share depends entirely on you and how you feel. Here are just a few suggestions based on conversations we've had with other young adults with diabetes.

DO	DON'T
DO ask if I need anything when my sugar is going low	DON'T ask me "should you be
DO ask me questions about diabetes when you are curious	eating that?"
DO treat me the same way you treat your other friends	DON'T look at/comment
DO respect my feelings about diabetes	negatively on my blood sugars

# EMOTIONAL WELLBEING: DEALING WITH "BURNOUT"

College can be mentally and emotionally demanding on its own. Add diabetes and it can be downright overwhelming.

But keep in mind—not only is it normal to feel burnt out by your diabetes sometimes, it should be expected. Here are some ways to try to avoid burnout, as well as how to deal with it when it comes up.



#### What is Burnout?

Burnout is a little bit different for everyone, but basically, it's when you're sick of your diabetes. We know, that sounds like every day, right? But there is a difference between your everyday annoyances with diabetes and burnout. Our students have described it in a few different ways. They were overwhelmed, frustrated, and exhausted. For some students, they stopped taking their meter with them to class—or just stopped checking altogether. They didn't rotate their pump sites. The list goes on.

#### **How to Deal**

**Connect with others.** This is where joining a CDN Chapter might come in handy. There are tons of blogs on the subject, too. Check out the blogs on our website to read stories from other students who have been there.

- Stay motivated, not 'perfect'. Many people with diabetes feel like they should always have blood sugar readings in their target range, and become frustrated when, despite their best efforts, they don't reach their goals. This doesn't have to be a source of stress if you accept the fact that "good" diabetes care doesn't mean being perfect. If you forgive yourself for the occasional blood sugar fluctuation, you'll be relieved of the stress associated with trying to achieve perfection. You'll likely reap more rewards from this approach in the long-term.
- ▶ Find ways to relieve stress. Exercise, writing, reading, drawing, painting—take some time to do something that you love. It will help.
- Now when to seek professional help. If you're experiencing extreme mood swings, depression, or helplessness, it's important to talk to a professional. People with diabetes are most at risk for conditions like anxiety and depression. Some students need support dealing with their anger surrounding diabetes, others with feelings of shame over 'out of range' blood sugar readings. Your parents, doctor, or a counselor/therapist who is familiar with diabetes can help you create strategies to relieve some of the burden. Most universities have free counseling services available to their students. Contact your school's health services to find out what type of counseling they offer. You can also check out the ADA's Mental Health Provider Directory Listing at https://professional.diabetes.org/mhp\_listing.

#### **DRINKING WITH DIABETES**



#### **Talk to Your Doctor**

Be sure to get your medical team's recommendations about whether drinking alcohol is safe for you. Even if you are under 21. They aren't there to judge you (or tell your parents).

#### Glucagon Will Not Help Treat Alcohol-induced Hypoglycemia

After a few drinks, your liver's primary function is cleaning the alcohol from your blood, not producing and releasing glucose. Glucagon will not work until your liver has finished this process.

#### **Carry Identification That Says You Have Diabetes**

This can be a medical alert bracelet, necklace, or a wallet card.

#### **Know Your Drinks**

- Know the carbohydrates in juices, sodas, and mixers.
- Know the alcohol proof of beer, wine, and distilled spirits.

#### **Educate Your Drinking Buddies**

Your drinking buddies should know you have diabetes and what to do in an emergency. Remember, a low looks a lot like being drunk and if nobody around knows that you have T1D, they may assume you are passed out from being wasted.



#### **Eat a Snack**

Never drink on an empty stomach. Once you start drinking, your liver will stop producing glucose and you'll need glucose from food to prevent hypoglycemia.

#### **Be Prepared**

- Bring your blood sugar testing kit.
- Bring glucose tablets or gels.
- Make sure your drinking buddies know what to do if you go low.
- ▶ Have a plan to get home.

#### **Check Your Blood Sugar**

You know why. Just do it

#### **Exercise & Alcohol**

Both exercise and drinking lower blood sugar levels. Pro tip: Dancing counts as exercise so check your blood sugar often!

#### **After the Party**

Remember—alcohol can lower your blood sugar hours after you've consumed it. Before you go to bed, check your blood sugar, have a snack, and/or consider setting a temporary basal rate on your pump. If you drank a lot, consider setting an alarm to help wake you up so you will test your blood sugar in the middle of the night.

<sup>\*</sup>Thank you to the folks at DrinkingWithDiabetes.com for their help on this page. Learn more about drinking and diabetes at **drinkingwithdiabetes.com** 

# As you turn 18, you may be wondering who can be notified in the event of a medical emergency

(or how your parents can intervene if you are unconscious).

Let's look at a common scenario that many young adults with T1D worry about. This will help you better understand what legal documents might assist your family if you have an emergency.

#### **Scenario**

While away at school, you come down with the flu, causing you to develop ketones and go into DKA. You are then brought to the emergency room. Because you are over the age of 18, the doctor is unable to give anyone (including your parents, friends, or resident assistant) information about your health because of HIPAA, a federal law that protects patients' privacy.

In this case, it may be useful to look into implementing a HIPAA Right of Access document, which allows you to decide who has access to your protected health information. If you name your parents on the HIPAA Right

of Access form, your parents would be able to speak with your doctor about your condition and treatment.

# A HIPAA Right of Access Document

allows you to determine what types of medical information you are comfortable with sharing via your healthcare providers. Some of the common rights of access you may want to grant others include the ability to: make or change medical appointments; order medical supplies; pick up lab reports; allow them to speak to medical providers in case of an emergency; discuss your treatment and management options with your doctor; and be present during appointments or medical consultations.



However, the HIPAA Right of Access form DOES NOT give anyone appointed access the power to make medical decisions. So, in the case that you are in the hospital because of DKA, your parents (or whoever is appointed access) would be able to have as much access to your health information as you would like, but they would not be able to actively make medical decisions on your behalf.

Another legal option that you may think to implement in this type of situation includes a **Medical Power of Attorney**, which may be called something slightly different depending on your state. A Medical Power of Attorney is essentially a legal document that allows an individual to select who they would want to make medical decisions for them if they are unconscious and unable to make the decision themselves.

It is important to note that if you do end up in in any kind of life-threatening situation, healthcare providers will typically do whatever it takes to keep you alive because you are so young. Therefore, a Medical Power of Attorney may not be necessary unless you have specific requests for medical procedures or care that you DO NOT want to be carried out (for example, being put on life support).

Keep in mind that a Medical Power of Attorney requires you to think about end of life treatments (no food, no resuscitation, etc.) and typically is not in effect until incapacitation occurs. In most situations, students find that implementing a Medical Power of Attorney may not be the appropriate legal document for their needs at this time, mainly because this document is aimed towards people who are at the end of their lives and/or have specific requests of how they would like their end of life decisions made. For the student who is hoping to have their parents involved on their own terms, a HIPAA Right of Access form is often sufficient for their needs.

#### ENTERING THE WORKING WORLD

## Welcome to the 'real' world!

As you prepare to launch yourself into your career or maybe find a new one, check out the resources below to help you navigate your options and know how to protect your rights in the workplace.

#### **American Diabetes Association**

You have the right to reasonable accommodations in the workplace. The American Diabetes Association website, **diabetes.org** [Living with Diabetes>Employment Discrimination], explains what accommodations you can ask for, and how to ask for them.

#### **We Are One Community**

Many people with T1D are inspired to pursue careers around diabetes in some way because of their personal experience with the disease. "We Are One" is a unique group of individuals who are both living with diabetes and working in the diabetes space. Bringing diabetes professionals living with T1D together is the main purpose of this online community created by Taking Control Of Your Diabetes (TCOYD).

We Are One is for everyone professionally involved with and living with T1D—medical professionals, people who work in the pharmaceutical or device industries, bloggers, other social media folks, journalists, authors, and so on. If you are in the diabetes 'space' and have T1D, We Are One will serve you well: weareonediabetes.org

#### **Looking for in-depth info on working with T1D?**

Check out the College Diabetes Network "Off to Work" Guide on our website to learn about your rights on the job, how to handle T1D in an interview and on the job, health insurance, financial planning, and more!



#### **TECHNOLOGY ON CAMPUS**

College often means an ever-changing and spontaneous lifestyle. Current technologies can help make navigating that environment with diabetes easier. Let's face it, we don't have much control over life with diabetes, but one of the perks of growing up is that you get to take control of choices like this.

#### **Insulin Pumps**

While your treatment needs will change throughout your lifetime, we are big fans of the benefits insulin pumps provide for the college lifestyle.

Pumps have temporary basal rates so you can easily and quickly decrease your basal (avoiding those late night lows after a night out) or increase it for a period of time (finals week stress).

They also offer options for extended boluses. When you hit the dining hall for that late-night pizza you can extend your meal bolus to avoid those pesky blood sugar spikes hours later.

These small devices subcutaneously deliver insulin via a small cannula in your skin that is changed every few days. Here are a few things you may want to do before making your decision:

- ▶ Research what's best for your lifestyle.
- ▶ Talk to your care team about options.
- Contact pump companies to speak with a medical representative. Usually you can test out different pumps and the representative can help you collect the necessary paperwork.

CGM is the most important advancement for people with type 1 diabetes since the discovery of insulin.

DR. STEVE EDELMAN

#### **Things to Consider**

There are many options out there if you have decided that you would like to give a pump and/or a Continuous Glucose Monitor (CGM) a try. The most important thing to consider is what is best suited to your lifestyle. When you do make your decision, be sure to update your school's Disabilities/Auxiliary Services so they have the most updated information about your diabetes management technology.

- **Built-in CGM** If you're in the market for an insulin pump with a built-in CGM, you have several options these days!
- ▶ Touch Screen Who needs buttons?
- ▶ **Tubing** Different tubing lengths are available to fit your needs and lifestyle, and patch pumps provide the option of tubeless pumping.
- Watertight Live in a warm place near the beach? Play a water sport? You might want a watertight pump.

Remember, technology is always changing. Be sure to check with your doctor about the newest pump options out there.

#### **Continuous Glucose Monitors (CGMs)**

CGMs are exactly what they sound like—small devices that constantly monitor your blood glucose using a small sensor that is inserted under the skin. Here are a few of the benefits of using a CGM while you're away at school.

- Constant monitoring of blood sugar and alerts can help ease your mind and your parents'.
- CGMs will alert you when your blood sugar is low, alleviating the fear of a serious low when you're living alone.
- ▶ CGMs are small and easily concealed and transported (perfect for a night out!).
- Because they are always attached to you, CGMs can identify trends in your blood sugar—making it much easier for you or your doctor to make adjustments that help you feel your best.
- CGMs give you the option to share your glucose data with parents, friends, or doctors.

FACT Whether a person with T1D takes shots or uses a pump, using a continuous glucose monitor has been shown to improve blood sugars and lower A1c. Source: T1D Exchange 2015

If you use a CGM or connected blood glucose meter, technology has made it possible to share your data easily (even in real time) with whomever you choose.

The decision of whether or not to share is a personal one. Your health data belongs to you alone—and it is up to you to decide if and when to share, and who to share it with.

Some students choose to share their data with their parents because it can help ease their worries and provide them with a familiar support system. But when going off to college, this topic can often come down to a balance of respect and privacy, and openness and support. You can also choose to share your data only when you are sick, asleep, or going out at night. The choice is yours. And remember, your parents aren't the only option for sharing your data—a friend can be a great share option too!

If you do decide to share your data, be sure to have a conversation about boundaries and mutual respect. Setting appropriate expectations about how and when to react and respond to the data they receive can help avoid arguments and nagging later on. Keeping the lines of communication open can help during times of stress, when you may decide to suspend data sharing for a while, or when you need more support than usual.

# What are the benefits of sharing?

If you haven't decided if you want to share this information with your family, here are some reasons why you should consider it:

- If you have trouble hearing the alarm on your CGM when you are dropping low or high, your family will also get alarms and can contact a friend or campus safety if they need to.
- Instead of having to text them what your blood sugar is, they can check for themselves.
- It can provide an extra level of security in case you need them for an emergency.
- It can reduce the stress associated with being constantly aware of notifications and alarms.

  If anything begins to go wrong, you'll have another set of eyes watching out for you.

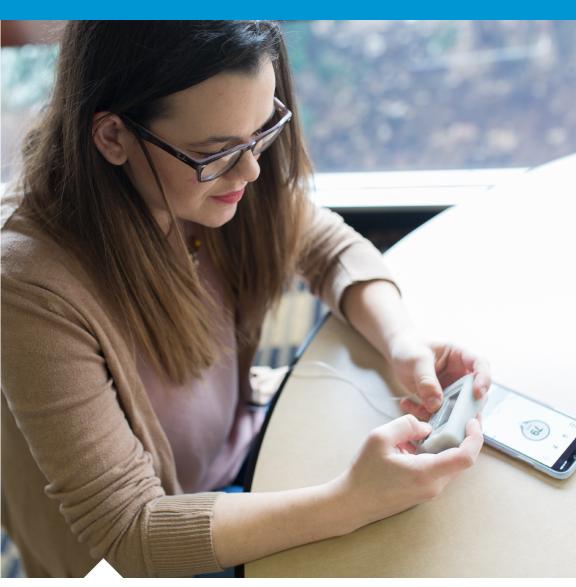
Keep in mind that not everyone will necessarily want you to share your data with them. For some, the responsibility and data overload can be overwhelming. This doesn't mean they don't love or care about you. Make sure you have honest conversations with anyone you choose to share with about their needs as well as your own.



#### **Student Spotlight**

#### **COURTNEY**

**Bryant University** 



Courtney goes to Bryant University, and uses "share" technology with her parents to keep in touch about her diabetes while she is away at school. Hear from Courtney about how her and her parents navigate this useful but sometimes anxiety-inducing management tool.

"

My parents and I agreed on an overnight system because I don't wake up to low blood sugars (even with my Dexcom). I manage everything completely during the day. Our system is a 15-minute rule where if I wake up and send a random Emoji to my parents, they know I'm treating my low. If I don't answer for 15 minutes they try calling me, then my roommate, and finally DPS, my school's on campus security system. I can't say I've loved the two times I've been woken up by security, but it is reassuring to know that my parents will do whatever they can to make sure I'm safe. And as embarrassing as it can be, I'm healthy and alive because of those dramatic wake up calls.

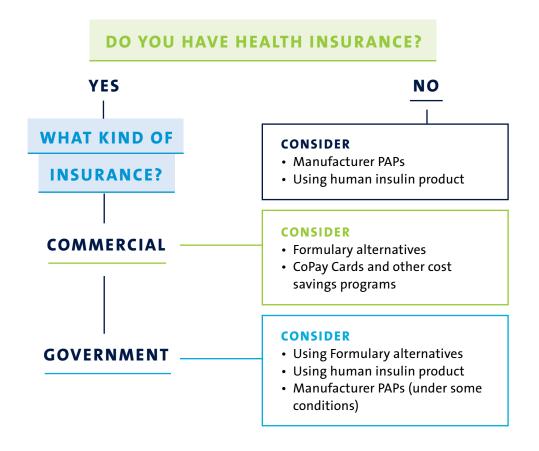
[My roommate] only turns the alarms on for weekends or sick days if my numbers are crazy, but it meant the absolute world to me that she wanted to keep tabs and help me manage it in every aspect she could.

COURTNEY

#### Insulin Affordability—What are your options?

Diabetes is expensive. It's estimated that people with diabetes have healthcare costs totaling almost three times that of people without diagnosed diabetes. The healthcare marketplace is often confusing. People with type 1 diabetes and many people with type 2 diabetes have no choice but to take insulin to stay alive. For individuals with inadequate, or no insurance coverage, the cost of insulin can be a major burden and barrier to staying healthy.

Here are some options to consider if you find yourself in those situations:



#### FOR MORE INFORMATION ON INSULIN AFFORDABILITY VISIT:

 $college diabetes network.org/patient\hbox{-} assistance\hbox{-} programs$ 

for links to more resources, specific manufacturer programs, and other organizations dedicated to insulin access.

#### **Formulary Alternatives**

## **Good for:** *Individuals covered under commercial or federal insurance plans*

Many insurance plans provide preferred coverage to certain drug manufacturers over others. For example, your plan may cover fast-acting insulin in the form of Humalog, but not Novolog, or vice-versa. In most cases, going with the preferred brand on your plan's formulary (list of covered drugs) will be the most affordable and hassle-free option. However, there are some cases where that isn't acceptable based on individual needs. In this case, work with your doctor to obtain a prior authorization for the brand that you need.

#### **Co-Pay Cards**

### **Good for:** *Individuals covered under commercial insurance*

Co-pay cards are coupons offered by drug manufacturers that cover all or some of the cost of co-pays at the pharmacy. Most co-pay cards are available for specific products, and usually individuals must already be enrolled in a commercial private insurance plan to qualify.

#### Patient Assistance Programs (PAPs)

#### Good for: Uninsured, qualifying individuals

Every major producer of insulin, including Eli Lilly, Novo Nordisk, Sanofi, and Mannkind, offers a PAP to aid qualifying individuals. Each have specific eligibility requirements, most often that individuals are not covered by any insurance plan, and fall within household income thresholds. If eligible, PAPs can provide prescriptions at little to no cost.

#### **Human Insulin Products**

# Good for: Uninsured individuals; people with inadequate coverage under commercial or government plans

Older formulations of insulin (referred to as "human insulin") are usually available over-the-counter at low cost from bigbox pharmacies such as Wal-Mart. These alternatives can be life-savers in an emergency, but it is important to understand that older formulations of insulin work differently than modern fast or long-acting insulin analogs, and therefore require special consideration regarding size and timing of dosing. For your own safety, talk to your doctor before using over-the-counter insulins.

#### I'M HAVING TROUBLE AFFORDING INSULIN. WHAT CAN I DO?

Talk to your medical care team. Your team is in the best position to help you according to your specific needs. They may have access to samples that they can provide you with until you and they can find a long-term solution.

Consider one of the options above. For more information on specific PAPs, co-pay cards, and other savings programs, visit your insulin manufacturer's website.

Rationing, diluting, or forgoing insulin is dangerous and life-threatening. There are always other options—don't give up. Reach out to your doctor, the Diabetes Online Community (DOC), or within your local community if you need help.

#### FIRST BREAK HOME

While you were probably itching to get out of the house and leave for college, the first break home can be a welcome relief from your hectic college schedule. However, coming home for the first time can sometimes bring up arguments between you and your parents about your diabetes management. While you may feel like a totally different person, your parents will probably still think of you (and your diabetes) the same way they did when you left.

During your first semester of college, you may have made some changes to your diabetes management or care routine. While these changes have become normal to you, this may not be the case for your parents, and they may have questions and concerns about your management and care.

While it can be irritating to feel like you're back to being "a kid" again, be open to explaining to your parents the choices that you have made and how it benefits your life and diabetes management. Your parents are asking these things out of concern for you and your health, not because they want to criticize you. Remember the communications plan you made with your parents, and try to stick to it at home as well. You may even want to develop a specific plan with your parents for how you will all handle the first break home. Below are some tips to help you get the most out of your break, and stress less about diabetes.

#### **ESTABLISH A PLAN**

Unless you discuss it beforehand, it's likely that when you come home you and your parents will fall back into old habits of diabetes management. Think about what you want out of your first break home, and discuss this with them before you get there. For example, if your parents used to do nighttime checks and you would rather they let you handle it over break, tell them. On the other hand, some students enjoy getting a "break" from diabetes when they are back home with their parents. It can be a relief to have someone help out when you've been doing it on your own these past few months. Whatever you decide, discuss it beforehand so that you are all on the same page.

#### **COMMUNICATE**

Your parents want to know what's going on in your life at college, and that includes diabetes! Be open with them about how things have been going, and don't be afraid to ask for help if you need it. If you've been struggling with fitting diabetes into your schedule, are feeling burnt out, or are having trouble finding a clinical provider at school that you like, talk to them. They may have ideas or strategies to help make your life a little easier.



#### **ENJOY THIS GUIDE?**

#### **CHECK OUT CDN'S OTHER GREAT RESOURCES!**



#### SIGN UP FOR STUDENT MEMBERSHIP ONLINE

Join the largest group of young adults with T1D at collegediabetesnetwork.org/join! CDN Members gain exclusive access to the complete range of information and resources for students and young adults. You'll be in the know about opportunities for jobs and internships, clinical trial and advisory board openings, and writing and interview opportunities from CDN and our partners. You'll also get awesome deals and discounts on diabetes products, accessories, apps and events to make life with T1D a little sweeter.



#### **JOIN OR START A CHAPTER ON YOUR CAMPUS!**

CDN Chapters are communities of students on college campuses across the country, started and led by students just like you. While their size and activities can vary from school to school, region to region, they all provide a way for students with type 1 diabetes (T1D) to connect with others who "get it". Any student with a connection to diabetes can start a Chapter - find or start one today by visiting collegediabetesnetwork.org/find-a-chapter.



#### **NEXTGEN LEADERSHIP OPPORTUNITIES**

Interested in working within the diabetes sector after college? Our NextGen Leadership Program is for you! CDN offers opportunities for students with diabetes to grow as leaders. Apply to attend a national diabetes conference with CDN over the summer, represent your Chapter at our annual Leadership Summit in April, or explore job, internship, and mentorship opportunities anytime on our website. Learn more at collegediabetesnetwork.org/nextgen.



#### **AMBASSADORS**

Looking for local support besides a Chapter? Connect with alumni, parents, and clinicians in your area through the CDN Ambassador program. Ambassadors can provide support to local students, parents, and Chapters. Ambassadors also help to raise awareness for CDN in other ways, like raising awareness, distributing materials and fundraising. Contact CDN to get in touch with ambassadors near you, or to learn more about becoming an ambassador yourself at collegediabetesnetwork.org/cdn-ambassadors.



#### OTHER RESOURCES FROM CDN

Visit collegediabetesnetwork.org/resource-hub to view more great guides just like this, including CDN's Off to Work guide - a comprehensive resource to help young adults with diabetes transition into professional life - and our Guide for Newly Diagnosed Young Adults - a primer on living with diabetes independently.



